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TITLE: Enhancing Involvement in Treatment Decision Making by Women with Breast Cancer

PRINCIPAL INVESTIGATOR: Mary Ann O'Brien, Timothy Whelan, Amiram Gafni, Cathy Charles, Ph.D., and Peter Ellis, Ph.D.

CONTRACTING ORGANIZATION: McMaster University
Hamilton, ON,L8N 3Z5

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Mary Ann O'Brien, Timothy Whelan, Amiram Gafni, Cathy Charles, Ph.D., and Peter Ellis, Ph.D.

E-Mail: maryann.obrien@hrcc.on.ca

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McMaster University
Hamilton, ON,L8N 3Z5

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14. ABSTRACT: Women with breast cancer desire more information about their disease, in part, to be involved in making treatment decisions (TDs). Patient involvement responds to patients' desires for autonomy and addresses ethical concerns about rights to make TDs. However, several researchers have reported that patients' actual experiences in TDM did not match their preferences. The study objectives are to 1) understand the meaning of involvement in TDM from the perspectives of women with early stage breast cancer (ESBC); 2) identify stages or steps of TDM used by women and their physicians during the treatment consultation(s); and 3) identify the behaviors of women and physicians that facilitate or impede women's involvement in TDM. **Methods**: A qualitative approach with interviews and video-stimulated recall is being used. In Phase 1, interviews with 19 women with ESBC were held to understand the concept of involvement in TDM. In Phase 2, consultations of a second group of 20 women are being digitally videotaped. Subsequently, women and their physicians (separately) view their consultation to identify any behaviors that facilitated or inhibited involvement in TDM. All interviews were taped, transcribed verbatim and analyzed. **Findings**: Phase 1: Most women wanted high quality information soon after diagnosis but many felt isolated and uninformed until the surgical or even the medical oncology visit. Most women thought they were heavily involved in a TDM process before, during and after the consultation. The results of the Phase 2 pilot testing indicated that videotaping the consultation was feasible. **Significance**: The information from this study will be useful to patients and physicians for promoting patient involvement. It can be used to develop and evaluate training programs for both physicians and patients to involve patients with cancer in decisions about their care.

15. SUBJECT TERMS
TREATMENT DECISION MAKING, VIDEO-STIMULATED RECALL INTERVIEWS, PATIENT PARTICIPATION, BEHAVIOR IDENTIFICATION

16. SECURITY CLASSIFICATION OF:			**17. LIMITATION OF ABSTRACT**	**18. NUMBER OF PAGES**	**19a. NAME OF RESPONSIBLE PERSON**
a. REPORT	**b. ABSTRACT**	**c. THIS PAGE**			USAMRMC
U	U	U	UU	40	**19b. TELEPHONE NUMBER** *(include area code)*

Table of Contents

Introduction

This report summarizes the research accomplishments of the first year of the Predoctoral Traineeship Award, from July 1 2005 to June 30 2006. The training studentship is a doctoral degree in Health Research Methodology at McMaster University in Hamilton, Canada.

The overall goal of the thesis proposal is to improve the opportunity for patient involvement in treatment decision making (TDM) for women with early stage breast cancer (ESBC). The specific objectives are 1) to describe the meaning of involvement in TDM from the perspectives of women with ESBC, 2) to identify the processes or stages of DM used by women and their physicians and 3) to identify the behaviors of women and their physicians that facilitate or impede women's involvement in TDM. In this report, the results of Task 1 (Objective 1) from the Statement of Work will be summarized. The first task was to complete patient recruitment, data collection and analysis for the Phase 1 patient interviews.

Statement of Work Task 1, Phase 1 (Patient Interviews): Patient Recruitment, Data Collection, and Analysis (Months 1-9)

Patient Recruitment: Initially, the PI met with medical and radiation oncologists at the study site, the Juravinski Cancer Center (JCC) to explain the purpose of the study and to gain the clinicians' support for patient recruitment. As well, the PI presented the study to primary nurses who were part of the clinical team to gain their support for the study and to enlist their help with the process to be used to identify eligible patients. Subsequently, a method to identify eligible patients was developed. Initially, the PI had proposed to contact eligible patients by letter after obtaining the permission of the clinician. However, the McMaster-Hamilton Health Sciences Research Ethics Board (REB) stipulated that all patients must be approached by a clinician. Therefore a different approach was used. The clinical features of all new patients were reviewed and those who appeared to meet the inclusion criteria (refer to the Phase 1 Eligibility Form in the Appendix) were identified by a research assistant. Prior to each eligible patient's scheduled visit, the oncologist was asked for his or her permission to approach the patient about the study. If the oncologist agreed, then the patient was approached by either the oncologist or the primary nurse. If the patient expressed interest in the study, then a research assistant explained the purpose of the study and obtained consent. For consenting patients, the PI telephoned each patient to request an interview appointment.

Theoretical sampling was also used in the study (Charmaz 2006; Glaser and Strauss 1967). Early in data collection, it became clear that patients viewed their interaction with their

surgeon as important in subsequent decision making with oncologists. For example, patients indicated that the decision to undergo radiation was made at the surgical visit when a choice was made between breast conserving surgery i.e. a lumpectomy plus radiation therapy, or a mastectomy. Therefore further data collection from patients attending the JCC for radiation therapy only was limited. Instead, a decision was made to recruit patients who were facing a surgical decision. Therefore, the study proposal was amended and sent to the REB requesting permission to enroll surgical patients scheduled to have breast cancer surgery at Hamilton Health Sciences or at St. Joseph's Hospital, both located in Hamilton, ON. The amended proposal was approved by the REB. For the surgical patients, as with the oncology patients, the clinician approached each patient to determine her interest in the study. Interviews were scheduled by telephone.

Data Collection

Pilot –Testing: The interview guide was pilot-tested with four patients who were completing either chemotherapy or radiation treatment. Subsequently, the guide was revised. Data collection for the study began shortly thereafter.

All patients who signed a consent form were interviewed by the PI using the revised interview guide. Interviews were held either at the JCC or in the patient's home according to the patient's preference. Each interview was audiotaped and transcribed verbatim. In addition, demographic and clinical data were collected (refer to the Demographic Form in the Appendix). After each interview, notes were handwritten then transcribed.

In general, patients were selected to be approached for the study if they met the inclusion criteria and the clinician agreed to approach the patient. As well, patients were selected in a purposeful manner so that both node-negative and node-positive patients in different age groups were included.

Analysis

The analysis was conducted using a grounded theory approach (Charmaz 2006; Glaser and Strauss 1967). A brief coding guide was developed. Initially two analysts independently coded two entire transcripts. The codes were compared and agreement was reached. In a similar manner, categories were generated from the codes, the results were compared, and agreement was reached. To check the stability of the process, a section from a third transcript was coded independently by the same two analysts and the results were compared. One

analyst coded the remaining transcripts. Substantive coding was used to identify themes and sub-themes from the data. Selective coding was used to identify a central theme and causal conditions that influenced the central theme and resulting actions.

This report contains a preliminary analysis of Phase 1 data since there was a delay in recruiting the surgical patients until REB approval was received. Data analysis is ongoing.

Results

Twenty-one women with ESBC were enrolled in this phase and 19 completed the study. Two patients declined to be interviewed after signing the consent form. Of the 19 women who completed the study, 10 made a chemotherapy decision, six made a surgical decision, and two made a radiation therapy decision. Of the women who made either a chemotherapy or radiation therapy decision, eight had node negative disease and four had node positive disease.

The following section highlights several examples of themes in the categories of involvement in decision making and processes of decision making.

Patient Involvement in Decision Making (DM) (examples)

- Women believed they were heavily involved in DM before, during, and after the treatment consultation. Women sought out information prior to the surgical or medical/radiation oncologist (M/RO) visit. During the consultation, they involved themselves in DM by listening to and clarifying information in light of the specifics of their tumor, asking questions, and by asking for a treatment recommendation. Women thought that they were responsible for the treatment decision although the surgeon or oncologist and the woman's family were important in the process.
- The treatment recommendation was important because of the surgeon's/oncologist's expertise. If the treatment recommendation was not stated explicitly, women tried to infer the surgeon's or oncologist's opinion based upon his/her choice of words or the order of presentation of options. Some women sought to verify the surgeon's or oncologist's expertise.

Decision Making (DM) Themes (examples)

- The DM process for adjuvant treatment began close to the surgical follow up visit. The surgeon was important to the DM process because he/she gave an opinion about the 'aggressiveness' of the cancer and the need for further therapy. Women formed an

expectation for what the M/R) would say in the consultation. If the treatment options that the M/RO gave were different from those expected, it was a source of confusion.

- Prior to the M/RO consultation, women sought information about treatment options from informal networks of friends who had experienced breast cancer.
- During the consultation, most women were overwhelmed by the amount of information they had received, making it difficult to process it.
- For most women facing a chemotherapy decision, information about the risk reduction associated with treatment was important to DM.

Key Research and Training Accomplishments

1. Successfully competed all PhD course requirements with an 'A' standing or higher.
2. Successfully completed the PhD comprehensive examination.
3. Thesis related tasks:
    a. Developed a process to identify ESBC patients.
    b. Completed pilot testing for Phase 1.
    c. Completed Phase 1 interviews of 19 women with early stage breast cancer that identified their involvement in TDM, processes or steps used by these women in TDM, as well as facilitators and barriers to their involvement in TDM.
4. As part of my training program, I participated in two other research projects that resulted in podium or poster presentations at conferences.
5. Also as part of my training program, I reviewed five manuscripts and one grant proposal in conjunction with my supervisor.

Reportable Outcomes

Conference Presentation Abstracts

2006 O'Brien MA, Whelan TJ, Charles C, Ellis P, Gafni A, Hasler A, Dimitry S. Enhancing involvement in treatment decision making by women with breast cancer. Reasons for Hope Breast Cancer Conference, Montreal, QC.

2006 Charles C, Ellis, PM, Dimitry, S, O'Brien, MA, Whelan, TJ. Agreement between physicians and patients about what constitutes shared decision-making. Proceedings of the American Association of Clinical Oncologists Annual Meeting, Atlanta, GE.

2006 Ellis PM, Dimitry S, O'Brien MA, Charles C, Whelan, TJ. A comparison of patient and physician attributes that promote patient involvement in treatment decision

making in the oncology consultation. Proceedings of the American Association of Clinical Oncologists Annual Meeting, Atlanta, GE.

2006 Ellis P, Dimitry S, Charles C, O'Brien MA, Whelan TJ. Identifying patient, physician and other attributes that promote patient involvement in treatment decision-making in the oncology setting. Hamilton and Region Qualitative Health Research Conference, Hamilton, CA.

Submitted Abstracts

2006 O'Brien MA, Whelan TJ, Charles C, Ellis P, Gafni A, Hasler A, Dimitry S, Lovrics P. Enhancing involvement in treatment decision making by women with breast cancer. Submitted to the Society for Medical Decision Making, Boston, MA.

Conclusions

In summary, considerable progress has been made during the first year of the Predoctoral Traineeship Award as noted in the section on Key Research and Training Accomplishments. All PhD course requirements have been successfully completed as has the comprehensive examination. The study has received the support from the oncologists and nurses at the JCC as well as surgeons at HHS and St. Joseph's Hospital. This support is crucial to the successful completion of the next phase of the study i.e. the video-stimulated recall interviews. Data collection is complete for Phase 1 and a preliminary analysis has been completed.

References

Charmaz K. Constructing grounded theory. Sage Publications, Thousand Oaks, CA., 2006.
Glaser B and Strauss A. Discovery of grounded theory: strategies for qualitative research. Aldine Publishing Company, Chicago, IL., 1967.

Appendices

1. Phase 1 Eligibility Form
2. Phase 1 Demographic Form
3. Phase 1 Interview Guide
4. CV
5. Abstracts

Appendix 1: Phase 1 Eligibility Form

Enhancing Involvement in Treatment Decision Making by Women with Breast Cancer

Patient Initials: __ __ __ **Phase 1** **Study ID Number: __ __ __ __**

ELIGIBILITY ASSESSMENT

To be completed for all patients who meet the Inclusion Criteria

SECTION 1: INCLUSION CRITERIA

Answer EACH criterion listed below:

The patient:	YES	NO
1a) Is female.	❑ 1	❑ 2
1b) Has histologically documented invasive carcinoma of the breast.	❑ 1	❑ 2
1c) Is likely to be Stage I, Stage II, or Stage III a and eligible for surgery, chemotherapy or radiation therapy.	❑ 1	❑ 2

If all answers are "Yes" continue to SECTION 2. If at least one "No" answer, patient is not eligible, do not continue.

SECTION 2: EXCLUSION CRITERIA

Answer EACH criterion listed below:

The patient:	YES	NO
2a) Is likely to be Stage III b, c or Stage IV	❑ 1	❑ 2
2b) Is unable to speak or understand English fluently (including visual impairment).	❑ 1	❑ 2
2c) Is mentally incompetent including any psychiatric or addictive disorders that would preclude taking part in an interview.	❑ 1	❑ 2

Continue to SECTION 3

SECTION 3: ELIGIBILITY STATUS

3a) Is the patient eligible to participate in the study?
(i.e., all Inclusion Criteria are answered "Yes" and all Exclusion Criteria answered "No")

❑ 1 Yes → *Continue to SECTION 4 PATIENT CONSENT*

❑ 2 No → *Sign and date form*

SECTION 4: PATIENT CONSENT

4a) Has the patient provided written informed consent?

❑ 1 Yes → **Include**

❑ 2 No → *Please provide reason:*

- o 1 Physician did not want the patient to be approached
- o 2 Patient did not want to consent
- o 3 Other: _____

SECTION 5: Identification

Study ID Number: __ __ __ __

Cancer Centre Chart Number: __ __ · __ __ __ __ __ __

Date of Eligibility Assessment __ __ / __ __ __ / __ __ __ __
day *month* *year*

Signature of person completing form: _____

Date form completed: __ __ / __ __ __ / __ __ __ __
day *month* *year*

Appendix 2: Phase 1 Demographic Form

Enhancing Involvement in Treatment Decision Making by Women with Breast Cancer

Patient Initials: _ _ _ **Phase 1** **Study ID #:** __ __ __

DEMOGRAPHIC INFORMATION QUESTIONNAIRE

To be completed by researcher assistant after interview

SECTION 1: BACKGROUND

1. Date of Completion: ___ ___ / ___ ___ ___/ ___ ___ ___ ___
   day *month* *year*

2. Cancer Centre Chart Number: __ __ • __ __ __ __ __ __

3. Date of Birth: __ __ / __ __ __ / __ __ __ __
   day *month* *year*

4. What is your present marital status? *Please check (✔) one answer below:*

   ❑ 1 Single (never married) ❑ 4 Separated

   ❑ 2 Married ❑ 5 Divorced

   ❑ 3 Living Together ❑ 6 Widowed

5. What is the highest level of education that you have completed? *Please check (✔) one answer below:*

   ❑ 1 No Formal Education ❑ 6 Some College / University

   ❑ 2 Some Public School ❑ 7 College / University Graduate

   ❑ 3 Public School ❑ 8 Post-Graduate

   ❑ 4 Some High School ❑ 9 Other, *Specify*: _____

   ❑ 5 High School Graduate

6. Will you be having any treatment for breast cancer?

❑ 1 Yes ❑ 2 No

If Yes, what treatment (s) will you be having? (Check all that apply)

❑ 1 Chemotherapy

❑ 1.1 AC ❑ 1.2 ACT ❑ 1.3 CMF ❑ 1.4 Other, Specify. _____

❑ 2 Radiation

❑ 3 Hormone Therapy

❑ 4 Surgery

❑ 4.1 Lumpectomy ❑ 4.2 Mastectomy ❑ 4.3 Other, *Specify*: _____

7. Are you participating in any research studies besides this one?

❑ 1 Yes ❑ 2No

If yes, what is the study? _____

8. Has a close relative or friend had cancer?

❑ 1 Yes ❑ 2 No If Yes, *Specify*: _____

9. Have you had cancer before?

❑ 1 Yes ❑ 2 No If Yes, *Specify*: _____

SECTION 2: TUMOUR DATA

a) Pathological size of tumour: __ __ . __ cm

b) Total number of axillary lymph nodes examined: __ __ nodes examined

a) Total number of positive lymph nodes: __ __ positive nodes

b) Overall tumour grade: ❑ 1 Grade I ❑ 2 Grade II ❑ 3 Grade III

c) Lymphovascular Invasion: ❑ 1 Present ❑ 2 Absent

❑ 3 Not Mentioned ❑ 4 Other, *Specify:* _____ __

d) Method of Hormone Receptor Determination: ❑ 1 Biochemistry ❑ 2 Immunohistochemistry
(Check only one, if both done check the one used for clinical decision making)

ii) ER Status: ❑ 1 Negative (1-9 fmol/mg) ❑ 2 Positive (10+ fmol/mg) ❑ 3 Not Done

iii) PR Status: ❑ 1 Negative (1-9 fmol/mg) ❑ 2 Positive (10+ fmol/mg) ❑ 3 Not Done

SECTION 3: MENOPAUSAL STATUS

Status (C*heck one):* ❑ 1 Pre-menopausal *(has regular periods and includes peri-menopausal)*

❑ 2 Post-menopausal *(has not had a period in the last six months)*

SECTION 4: CONSULTATION

a) Which oncology team assessed the patient?

❑ 1 I. D ❑ 6 M. L

❑ 2 B. D ❑ 7 B. S

❑ 3 P.E ❑ 8 J. S

❑ 4 B.H ❑ 9 R. T

❑ 5 N. H ❑ 10 Other Specify: _____

Signature of person completing form: _____

Date form completed: __ __ / __ __ __ / __ __ __ __
day *month* *year*

Appendix 3: Phase 1 Interview Guide

Study Title: Enhancing Involvement in Treatment Decision Making by Women with Breast Cancer

Phase 1: Patient Interview Guide

Opening Question

1. Can you tell me about any discussions you have had with your doctors about your treatment for cancer?

Decision making process related to cancer treatment

2. In your situation, do you feel that there were decisions that were made about your treatment?
    a. *Prompts*: If yes, can you tell me about the decision that was made?
    b. *Prompts*: If no, can you tell me why you felt there was no decision to be made?

If there was a decision about treatment

3. In your situation, can you describe the process of making the decision about treatment?
    a. *Prompts*: Possibilities: asking for and receiving information about treatment options, deliberating over the options, making the decision.
    b. *Alternative questions*: How was a decision about treatment made? How did you decide what to do?

4. Would you describe what happened as a sequence of steps?
    a. *Prompts*: If yes what were the steps?
        i. If yes, how do these steps relate to each other (a sequence, steps happening simultaneously?)
        ii. Was one step more important than another?
    b. *Prompt*: If no, how did you arrive at a treatment decision?

5. Who was involved in the process of making the decision?
    a. *Prompts*: Patient, doctor, primary care nurse, family, others?

6. Where did the process of decision making take place?
    a. *Prompts*: At home, at the cancer centre, both places?

7. When did the process of decision making first start?
    a. *Prompts*: When patient had symptoms, at the surgeon's office

8. Has the process of decision making ended?
    a. Prompts: If yes, when did it end?

b. If no, why is that?

9. Who made the decision about which treatment to implement?
    a. Prompts: You, the patient, both, other people

I'd like to ask you about patient involvement in the process of making a decision about treatment.

10. What does patient involvement in the process of making a decision about treatment mean to you?

11. Did you feel that you were involved in the process of making a treatment decision?
    a. *Prompts*: If yes, how did you take part? Was it how you wanted to take part in this process of making a decision about treatment?
    b. *Prompts*: If no, why was that? Did you take part more than you wanted or less than you wanted? If more than you wanted, how did that happen? How did you feel about taking part more than you wanted? If less than you wanted, how did that happen? What sorts of things prevented you from taking part?

12. If you participated in the process of making a decision as much as you wanted, did anything happen to encourage you to take part?

13. Did the doctor say or do anything to help you to take part in the process of making the decision about treatment?

14. Did the doctor say or do anything to discourage you from taking part in the process of making the decision about treatment?

15. Is there any feature about you as a person that helped you to take part in the process of making the decision about treatment?
    a. *Prompts*: For example, a patient who wants to know all treatment details or does not want to know; The patient's previous personal or family member's experience.

16. Is there any feature about you as a person that acted as a barrier to you taking part in making a decision about treatment?

17. Is there anything you said or did that helped you to take part in the process of making the decision about treatment?

18. Is there anything that you said or did that acted as a barrier to taking part in the process of making the decision about treatment?

19. Did your involvement in the process of making a decision about treatment change since you first learned you had breast cancer?
    a. *Prompts*: When you saw the surgeon, when you saw the oncologist

20. Did you have enough time to take part in the process of making a decision about treatment?

21. Overall, now thinking about the decision making process, what is needed for a process that is high in quality?

22. How would you describe the quality of the decision making process that you used?
    a. *Prompt*: Why do you feel this way?

Closing

23. Is there anything else you would like to tell me about your situation of making a treatment decision?

Thank you once again for participating in my study.

Appendix 4: CV

CURRICULUM VITAE

NAME: O'Brien (Thomson), Mary Ann

ADDRESS: Business
Supportive Cancer Care Research Unit
Juravinski Cancer Centre
699 Concession Street
Hamilton, Ontario
L8V 5C2
voice mail: (905) 387-9711 ext 64502
email: maryann.o'brien@hrcc.on.ca

EDUCATIONAL BACKGROUND

2003 PhD in progress (commenced September 2003)

1995 MSc (Design, Measurement and Evaluation), McMaster University, Hamilton, Canada

1984 BHSc (Physiotherapy) McMaster University, Hamilton, Canada

1978 Diploma in Physiotherapy, Mohawk College, Hamilton, Canada

Certificate in Physiotherapy, McMaster University, Hamilton, Canada

CURRENT STATUS AT MCMASTER UNIVERSITY

2001-2006 Associate Clinical Professor, School of Rehabilitation Science

1998-2001 Assistant Clinical Professor, School of Rehabilitation Science

1992-1997 Clinical Lecturer, School of Rehabilitation Science

EMPLOYMENT HISTORY

ACADEMIC

2000- 2003 Senior Research Manager, Supportive Cancer Care Research Unit, McMaster University

1999- 2000 Research Co-ordinator, Evidence-based Practice Centre, McMaster University

1998-1999 Research Co-ordinator, McMaster University and Social and Public Health Services Division, Region of Hamilton-Wentworth

1997-1998 Senior Research Fellow, Department of Public Health, University of Aberdeen, United Kingdom

1996-1997 Research Fellow, Department of Health Sciences and Clinical Evaluation, University of York, United Kingdom

1985-1991 Clinical Education Co-ordinator, Mohawk-McMaster Physiotherapy Program, Mohawk College of Applied Arts and Technology, Hamilton, Ontario

CLINICAL

1999- Physiotherapist, Hamilton Health Sciences

1996-1997 Evaluation Specialist, Re-engineering Department, Chedoke-McMaster Hospitals

1991-1996 Education Manager, Physiotherapy Services, Chedoke-McMaster Hospitals

1985-1991 Clinical Education Co-ordinator, Chedoke-McMaster Hospitals, McMaster University Medical Centre Division

1983-1985 Senior Physiotherapist, Chedoke-McMaster Hospitals, McMaster University Medical Centre Division

1978-1983 Staff Physiotherapist, Chedoke-McMaster Hospitals, McMaster University Medical Centre Division

AWARDS AND FELLOWSHIPS

2005 – 2008 Predoctoral Traineeship Award, US Department of Defense, Breast Cancer Research Program

2004 – 2006 Doctoral Fellowship, Canadian Breast Cancer Foundation – Ontario Chapter (declined Year 2)

2004 – 2007 Doctoral Studentship, National Cancer Institute of Canada (declined)

2004 – 2005 Ontario Graduate Student Award, (declined)

SCHOLARLY AND PROFESSIONAL ACTIVITIES

1997- Peer Reviewer
Grants: National Health Service Research & Development Programme, National Health Service Health Technology Assessment Programme, United Kingdom
Manuscripts: American Journal of Public Health, Health and Social Care in the Community, Journal of Epidemiology and Community Health, Medical Care, Quality in Health Care

1995-2002 Member, Board of Examiners, Physiotherapy National Exam.

1995-1997 Chief Examiner, Clinical Component, Physiotherapy National Exam, Toronto Site.

1991-1995 Member, Clinical Education Group, Physiotherapy Programme, School of Occupational Therapy and Physiotherapy, McMaster University, Hamilton, Ontario.

1990-1995 Chair, Station Development Sub-Committee, OSCE Test Construction and Implementation, Canadian Alliance of Physiotherapy Regulatory Boards.

AREAS OF INTEREST

RESEARCH

Attributes of the clinical encounter that facilitate treatment decision-making
Effectiveness of interventions to improve health professional practice
Factors influencing the adoption of research evidence into health professional practice

TEACHING

Finding the best available evidence and incorporating it in clinical practice

COURSES TAUGHT

McMaster University (Graduate)

2004-	Lecturer, Inquiry Seminar, MSc. PT Programme
2003- 2003	Tutor, Unit Three, Introduction to Cardio-pulmonary and Neurology, MClSc PT Programme
2000	Co-Advisor with A Jadad, Research Internship, Health Research Methods Programme

University of Aberdeen (Graduate)

1997	Lecturer, Health Services Research

McMaster University (Undergraduate)

2001	Tutor, Unit Four, Cardio-pulmonary, BHSc. PT Programme
2000- 2003	Inquiry Seminar, BHSc. PT Programme
2000	Advisor, Unit Six Research Internship
1998-1999	Tutor, Unit Four, Cardio-pulmonary, BHSc. PT Programme
1996	Advisor, Unit Six, Independent Study, BHSc. PT Programme
1993-1995	Tutor, Unit Four, Cardio-pulmonary, BHSc. PT Programme
1992	Advisor, Block Six, Independent Study, BHSc. PT Programme
1990-1992	Tutor, Block One, Introduction to Musculo-Skeletal Problems, BHSc. PT Programme
1988	Tutor, H.S. 4B4/3B4, Health, Science and Society, BHSc Programme

Other

1988-1995	Tutor, Clinical Teaching Workshop, Program for Faculty Development, McMaster University, Hamilton, Ontario

Thesis Committee

2000	Jodi Herold. The effect of using an alternative method to calculate station cut scores in an objective structured clinical examination (OSCE). (Masters) University of Toronto.

LIFETIME RESEARCH FUNDING

GRANTS

Funded

Funding Agency: Canadian Health Services Research Foundation
Amount: $127,164
Funding Period: November 1 2004 to October 31 2006
Project Title: A Study of the Effectiveness of Specialist Oncology Nursing Case Management in Improving Continuity of Supportive Cancer Care in the Community

Investigators: Sussman J, Howell D, Brazil K, Whelan T, Green E, MacKenzie L, O'Brien MA, Wiernikowski J, Fitch M.

Funding Agency: Ontario Ministry of Health and Long-Term Care
Amount: $53,313.24
Funding Period: January 2004 – June 2004
Project Title: e-Health and mental Health Services: A synthesis of literature to identify best practices.
Investigators: Raina P, Eysenbach G, Suggs LS, McIntyre C, MacMillan H, McKibbon KA, O'Brien MA, Santaguida L.

Funding Agency: Ministry of Health and Long Term Care
Amount: $285,746
Funding Period: April 1 2003-March 31 2004
Funds Held in Department of Clinical Epidemiology and Biostatistics
Project Title: An Evaluation of the Effectiveness of a Specialized Nursing Case Management Program in Coordinating Supportive Cancer Care in the Community.
Investigators: Sussman J, O'Brien MA, Howell, D, Whelan T.

Funding Agency: Hamilton Regional Cancer Centre Foundation
Amount: $15,000
Funding Period: April 1 2003- March 31 2004
Funds Held at the Hamilton Regional Cancer Centre
Project Title: Can Physicians Accurately Record Breast Cancer Outcomes? A Quality Improvement Pilot Study.
Investigators: O'Brien MA, Whelan T, Strang B, Wiernikowski J, Banayan D, Eisen A, Sussman J, Ellis P, Dubois S.

Funding Agency: Ministry of Health and Long Term Care
Amount: $195,970/year
Funding Period: April 1 2001-March 31 2003
Funds Held in Department of Clinical Epidemiology and Biostatistics
Project Title: Identifying the best model to provide (coordinate) supportive cancer care in the community
Investigators: Brazil K, Whelan T, O'Brien MA, Sussman J, Pyette N.

Funding Agency: Agency for Healthcare Research and Quality
Amount: $350,000 ($US)
Funding Period: April 1 2001-March 31 2002
Funds Held in Department of Clinical Epidemiology and Biostatistics
Project Title: Diffusion and Dissemination of Evidence-based Cancer Control Interventions
Investigators: Ellis P, Raina P, Haynes RB, Brouwers M, O'Brien MA, Ciliska D, Browman G, Whelan TJ, Snider A, Rand C.

Funding Agency: Agency for Healthcare Research and Quality
Amount: $250,000 ($US)
Funding Period: April 1 2000-March 31 2001
Funds Held in Department of Clinical Epidemiology and Biostatistics
Project Title: Impact of Cancer-related Decision Aids
Investigators: Whelan TJ, Gafni A, Charles C, Jadad A, O'Brien MA

Funding Agency: Agency for Healthcare Research and Quality
Amount: $300,000 ($US)
Funding Period: September 30 1999-September 29 2000
Funds Held in Department of Clinical Epidemiology and Biostatistics
Project Title: Management of Chronic Central Neuropathic Pain Following Spinal Cord Injury
Investigators: Jadad A, O'Brien MA. Snider A, Gauld M

Funding Agency: Canadian Health Services Research Foundation
Amount: $19,850
Funding Period: November 1999-November 2000

Project Title: Improving Communication Among Public Health Researchers and Decision and Policy Makers.
Investigators: Thomas BJ, O'Brien MA, Edwards N., Ciliska D., Dobbins M., Beyers J.

Funding Agency: CMH Physiotherapy Grant Fund
Amount: $9100
Funding Period: July 1996-July 1997
Funds Held in CMH Physiotherapy Department
Project Title: Diagnostic Validity of Clinical Tests in Temporomandibular Disorder: meta-analyses
Investigators: Gross A, Haines T, Goldsmith C, McIntosh J, Thomson MA.

Funding Agency: Heart and Stroke Foundation of Ontario
Amount: $100,600
Funding Period: July 1996-July 1998
Project Title: Stroke Strengthening Study
Investigators: Moreland J, Cook DJ, Goldsmith C, Thomson MA, Huijbregts M, Anderson R, Prentice D.

Funding Agency: National Health Service, Research and Development, United Kingdom
Amount: $36,260 (CDN)
Funding Period: January 1996 - January 1997
Funds held at University of York, United Kingdom
Project Title: The Effectiveness of Continuing Education Conferences in Improving Health Professional Performance and Health Care Outcomes
Investigators: Thomson MA, Freemantle N, Oxman AD, Davis DA.

Funding Agency: Canadian Orthopaedic Foundation, Hip, Hip Hooray Grants Program
Amount: $915
Funding Period: July 1995-July 1996
Funds Held in CMH Physiotherapy Department
Project Title: Diagnostic Validity of Clinical Tests in Temporomandibular Disorder: meta-analyses (1995 update)
Investigators: Gross A, Haines T, Goldsmith C, McIntosh J, Thomson MA.

Funding Agency: Canadian Orthopaedic Foundation, Hip, Hip Hooray Grants Program
Amount: $2,735
Funding Period: July 1993 - June 1994
Funds held in Physiotherapy Department, Chedoke-McMaster Hospitals
Project Title: Lower Extremity Function Study
Investigators: Thomson MA, Moreland J, Balsor B, Kay, T.

Funding Agency: Edith Herman Research Fund, McMaster University, Hamilton, Ontario
Amount: $5,000
Funding Period: December 1993 - December 1994
Funds held in Faculty of Health Sciences, School of Occupational and Physiotherapy
Project title: Diagnostic Validity of Clinical Tests in Temporomandibular Disorders: Meta-analyses
Investigators: Gross A, Haines T, Goldsmith C, McIntosh J, Thomson MA.

Funding Agency: Hamilton District Research Fund, Ontario Physiotherapy Association, Hamilton, Ontario
Amount: $500
Funding Period: June 1992 to June 1993

Funds held by Hamilton District Treasurer
Project title: Diagnostic Validity of Clinical Tests in Temporomandibular Disorders: Meta analyses
Investigators: Gross A, Haines T, Goldsmith C, McIntosh J, Thomson MA.

Funding Agency: Hamilton District, Ontario Physiotherapy Association
Amount: $1,000.00.
Funding Period: January 1992 - December 1992
Funds held in Physiotherapy Department, Chedoke-McMaster Hospitals
Project Title: The Efficiency of EMG Biofeedback for Upper Extremity Function Following Stroke: A meta-analysis.
Investigators: Moreland J, Thomson MA.

Submitted

Funding Agency: CIHR
Amount: $1,348,086 (total 5 years)
Funding Period: October 1 2006 – September 30, 2011
Funds held in Department of Surgery, McMaster University
Project Title: Tailored Knowledge Exchange in Rectal Cancer (TKRC) Trial
Investigators: Simunovic M, O'Brien MA, Eva K, Whelan T, Koru-Sengal T, Goldsmith C, Thebane L, Lavis J, DeNardi F, Stern H, Smith AJ, Baxter N, Levine MN.

Unfunded

Title: The efficiency of EMG biofeedback for lower extremity function following stroke: a meta-analysis. Investigators: Moreland J, Thomson MA, Fuoco A. Location: Chedoke-McMaster Hospitals

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Invited

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1996 Thomson MA, Oxman AD, Haynes RB, Davis DA. No magic bullets: a systematic review for improving professional practice. Provincial Utilisation Management Co-ordinating Committee. Fredericton, New Brunswick.

1996 McKibbon A, Thomson MA. Identifying and retrieving information on physiotherapy interventions. Canadian Co-ordinating Office for Health Technology Assessment and the Canadian Physiotherapy Association. Toronto, Ontario.

1996 Thomson MA. Connecting research and practice: providing quality care. Neurodevelopmental Clinical Research Unit Research Day. Burlington, Ontario.

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1994 Thomson MA, Oxman AD, Davis DA, Haynes RB. No magic bullets: a systematic review of 102 trials of interventions to help health care professionals deliver services more effectively or efficiently. North East Thames Research and Development Conference, London, England.

1994 Thomson MA, Wakefield J. Educational methods and issues. Teaching and learning in the Clinical Setting. Boston, Mass.

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Appendix 5: Abstracts

2006, Reasons for Hope Breast Cancer Conference, Montreal, QC.

Enhancing Involvement in Treatment Decision Making by Women with Breast Cancer

Mary Ann O'Brien[1], Tim Whelan[1], Cathy Charles[2], Amiram Gafni[2], Peter Ellis[1]

Supportive Cancer Care Research Unit, McMaster University, Hamilton, ON[1]
Centre for Health Economics and Policy Analysis, McMaster University, Hamilton, ON[2]

Women with breast cancer have indicated a desire for more information about their disease, in part, to be involved about making treatment decisions (TDs). Patient involvement responds to patients' desires for autonomy and addresses ethical concerns about rights to make TDs. Importantly, patients who are involved in treatment decision making (TDM) are more likely to have their preferences incorporated in the TD. Despite patients' desires to be involved in TDM and the ethical and medical importance of this involvement, several researchers have reported that patients' actual experiences in making TDs did not match their preferences. Part of the problem may be that some models of TDM have not been developed from the patients' perspectives and little is understood about what involvement in TDM really means to patients. The study objectives are to 1) understand the meaning of involvement in TDM from the perspectives of women with early stage breast cancer (ESBC); 2) identify stages or steps of DM used by women and their physicians during the treatment consultation(s); and 3) identify the behaviours of women and physicians that facilitate or impede women's involvement in TDM. A grounded theory qualitative approach with interviews and video-stimulated recall is being used. Initially, interviews with 20 women with ESBC are being held to identify the meaning of involvement in TDM and the DM process used by these women. Subsequently, treatment consultations of a second group of 20 women are being digitally videotaped. Several days after the consultation, these women and their physicians (separately) view their own consultation to describe their DM process and identify the behaviours that facilitated or inhibited involvement in DM. All interviews are taped, transcribed verbatim and analyzed. This study will identify how women with ESBC want to be involved in the TDM process, any stages or steps of the TDM process, and patients' and physicians' behaviours that enhance involvement in TDM. This information will be useful to patients and physicians for promoting patient involvement. It can be used to develop and evaluate training programs for both physicians and patients to involve patients with cancer in decisions about their care.

2006, ASCO, Atlanta GE.

Agreement between physicians and patients about what constitutes shared decision making

C Charles, PM Ellis, S Dimitry, MA O'Brien, TJ Whelan.

Background
Involving patients in making decisions about their own care is increasingly desirable for patients with serious illness. Shared decision making is one such model, the attributes of which have been well defined (Charles et al., Soc Sci Med, 1997, 1999). However, it is unclear whether physicians and patients agree on what constitutes a SDM interaction.

Methods
Semi-structured interviews were undertaken with 21 medical and radiation oncologists and 14 cancer patients attending a regional cancer centre. Participants were asked what they thought it meant for the patient and physician to share in DM. Responses were compared to the theoretical constructs of SDM defined by Charles et al: information exchange (flow, direction, type, amount), deliberation, and who makes the decision. Two analysts independently reviewed the interviews for patient and physician definitions of SDM and compared these with the Charles et al, model of SDM using explicit classification decision rules. There were few discrepancies between analysts and agreement was reached in all cases.

Results
71% of physicians and 29% of patients described a two-way flow and direction of information exchange as necessary for SDM. Only 24% of physicians and 21% of patients described the exchange of both medical and personal information. All participants indicated that more than the minimum legally required amount of information was needed. 67% of physicians and 36% of patients described both patient and physician involvement in deliberation about treatment as a component of SDM. 48% of physicians and 21% of patients identified both patients and physicians are involved in deciding what treatment to implement in a shared approach. Overall, none of the participant definitions identified all the components of the SDM model. Physicians in their definitions, identified more components than did patients.

Conclusions
Physicians appear to have a stronger understanding of the elements involved in SDM. These differences may lead to different expectations about patient involvement in DM. Physicians have a responsibility for ensuring that patients are invited to contribute to all components of SDM in the oncology consultation.

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A comparison of patient and physician attributes that promote patient involvement in treatment decision making in the oncology consultation

PM Ellis, S Dimitry, MA O'Brien, C Charles, TJ Whelan

Background
Cancer patients have indicted a desire to be more involved in treatment decision making (TDM). However, little is known about the attributes of patients, physicians and their interaction that promotes patient involvement in TDM in the oncology consultation. This study compared attributes generated by patients and physicians that make it easier for patients to be involved in TDM.

Methods
Semi-structured interviews were undertaken with 19 patients with cancer (breast, prostate, lung, GI) and 21 medical and radiation oncologists at a regional cancer centre. Participants were asked to identify attributes of physicians, patients and their interaction that promotes patient involvement in TDM. Patient and physician interview transcripts were independently coded by 2 analysts using decision rules, to identify specific attributes. Attributes identified by each analyst were compared and a high level of agreement was found. The analysts then independently compared the physician and patient generated lists and identified common vs unique attributes. There was a high level of agreement on which attributes identified were common to both lists versus unique.

Results
Oncologists identified 173 physician, 59 patient and 9 interaction attributes. Patients identified 50 physician, 42 patient and 11 interaction attributes. Patients and physicians identified 17 common physician items, 29 common patients items and 1 common interaction item. Physicians identified 138 more attributes than patients, most of which were physician related. Common patient attributes centred on information seeking (eg prepare for the consultation by reading, be aware of all treatment options, question the treatment options). Common physician attributes focused on specific communication behaviors (eg, make eye contact, sit next to patient, tailor information to patient needs, be direct with patients, ensure patient understands information). The common interaction item was to keep the discussion informal.

Conclusions
Patients and physicians appear to have different ideas about what is important to promote patient involvement in TDM. Many of the attributes identified can be easily incorporated into current practice. There is a need to develop and evaluate communication skills training to promote patient involvement in TDM.

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Identifying patient, physician and other attributes that promote patient involvement in treatment decision-making in the oncology setting

P. Ellis, S. Dimitry, C. Charles, MA. O'Brien, T. Whelan

Many cancer patients have indicated a desire to be more involved in treatment decision-making (TDM). To date, little is known about the attributes that promote patient involvement in this process. The purpose of this exploratory qualitative study was to learn about these attributes from the perspective of both parties most intimately involved - patients and oncologists. A purposeful sample of 11 medical and 10 radiation oncologists and 19 consecutively recruited, male and female cancer patients aged 44-75 yrs., from four disease groups (breast, prostate, lung, GI) at various stages of illness (stages 1-4) were recruited from a regional cancer centre. Semi-structured individual interviews were undertaken with participants over a 12-month period. Each participant was asked to identify patient, physician, interaction and situational attributes that facilitate patient involvement in TDM. Interviews were transcribed verbatim. A rigorous and transparent process was used to identify and verify the facilitating attributes emerging from the interview data. Methodological and data management processes and decisions were routinely documented to form an audit trail. Explicit coding rules were developed to consistently identify and code relevant attributes within and across all transcripts into 4 major coding headings: physician, patient, interaction and situational attributes. In the pilot-testing phase, the coding rules were tested, refined and revised by three analysts until their application was clear and a high degree of inter-rater agreement was achieved. One analyst then coded each patient transcript, but as a second reliability check, 2 patient transcripts from each disease site were randomly chosen and coded by a second analyst with high agreement obtained. The 21 physician transcripts were independently coded by two analysts and also had a high level of agreement. The resulting attribute lists were reviewed by 37 additional patients from the same cancer centre, who participated in 6 focus groups. In total, patients identified 138 attributes and physicians identified 308 attributes. The next step in this research is to identify from the overall dataset of attributes that facilitate patient involvement in TDM, a key subset through data reduction activities and to incorporate these into two structured instruments for researchers and patients. Our findings will be important in helping to identify factors that facilitate patient involvement and in evaluating the extent to which these factors have been present in specific medical encounters.

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ENHANCING INVOLVEMENT IN TREATMENT DECISION MAKING BY WOMEN WITH BREAST CANCER

Mary Ann O'Brien[1], Tim Whelan[1], Cathy Charles[2], Peter Ellis[1], Amiram Gafni[2], Adrianne Hasler[1], Susan Dimitry[1], Peter Lovrics[3],

Supportive Cancer Care Research Unit, McMaster University, Hamilton, ON[1]
Centre for Health Economics and Policy Analysis, McMaster University, Hamilton, ON[2]
St. Joseph's Hospital, Hamilton, ON, CANADA[3]

Purpose: Women with breast cancer have indicated a desire for more information about their disease, in part, to be involved in making treatment decisions. Importantly, patients who are involved in treatment decision making (TDM) are more likely to have their preferences incorporated in the treatment decision. Despite patients' desires to be involved in TDM and the ethical and medical importance of this involvement, researchers have reported that patients' actual experiences in making decisions did not match their preferences. The study objectives are to 1) understand the concept of involvement in TDM from the perspectives of women with early stage breast cancer (ESBC); 2) identify any stages or steps of DM used by women and their physicians during the treatment consultation(s); and 3) identify the behaviors of physicians that facilitate or impede women's involvement in TDM. **Methods**: A qualitative approach with interviews and video-stimulated recall was used. In Part 1, interviews with 19 women with ESBC were held to develop the concept of involvement in TDM and the decision making process used by these women. In Part 2, treatment consultations of a second group of 20 women were digitally videotaped. Several days later, these women and their physicians (separately) viewed their own consultation to describe their DM process and identify the behaviours that facilitated or inhibited involvement in DM. All interviews were taped, transcribed verbatim and analyzed. **Results**: Part 1: Most women wanted high quality information soon after diagnosis but many felt that they were left in a void until the surgical or even the medical oncology visit. Most women thought they were heavily involved in a TDM process before, during and after the consultation. The results of the Part 2 pilot testing indicated that videotaping the consultation was feasible. Women liked the opportunity to review information presented in the consultation. They identified how they were involved in the DM process and different ways that the oncologist facilitated or inhibited their involvement. **Conclusions**: This study has identified women's perceptions of their involvement in the TDM process, how treatment decisions were made and physicians' behaviours that enhanced or impeded women's involvement in TDM. This information will be useful to patients and physicians for promoting patient involvement in TDM.